

Plan to Attend Disability to Ability 2002 !

Get ready — it's that time of year again. The Arkansas Spinal Cord Commission (ASCC) and the Spina Bifida Association of Arkansas will hold our 2002 conference **Friday, May 31** at the C.A. Vines 4-H Center in Ferndale. The conference entitled, "Disability to Ability," looks to be the best conference yet!



Randy Snow will be the keynote speaker at the May 31, 2002, conference to be held at the 4-H Center in Ferndale.

Randy Snow, noted paralympian and motivational speaker, will open the conference. Conference sessions will cover a variety of topics such

as spina bifida, sexual function, spasticity, wheelchair repair, depression and the cecostomy procedure. Exhibitors will be on hand to answer questions and discuss their new products and services. Free information on various subjects will be available at the resource table.

Lunch will be provided for all who pre-register.

Door prizes will be awarded at the end of the conference (you must be present to win). Also, continuing

education units (CEUs) will be available in many professional disciplines. A limited number of scholarships to cover the conference pre-registration fee and travel stipends are available to help individuals with spinal cord disabilities attend the conference.

Registration forms will be mailed out at the end of April. If you do not receive one in early May, please contact your ASCC Case Manager or call Mary Jo Stanton at **296-1788** or **1-800-459-1517**

Governor's Youth Leadership Forum for Students with Disabilities

Arkansas Rehabilitation Services and the Governor's Commission on People with Disabilities have announced the 2002 Governor's Youth Leadership Forum (YLF) for Students with Disabilities. The Forum is scheduled for **July 29 to August 2, 2002**, at the University of Central Arkansas in Conway.

Approximately 20 high school juniors and seniors with disabilities will be selected to attend. This exciting, fun, educational leadership training program includes a meeting at the Governor's office, a tour of the State Capitol and meet-

ings with community leaders. The content of the training aspect of the program will involve planning and goal setting, disability law, advocacy and the development of peer relationships.

The Youth Leadership Forum will cover all related expenses for attendees including travel, lodging, meals and interpreters or personal care assistants as needed. Applications for the YLF are due **May 3, 2002**.

For additional information and

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SPINAL COURIER

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www.state.ar.us/ascc
or e-mail us at:
arkscc@aol.com

With Thanks

Donations this quarter from:

**Charles and Linda Dyson
Bryan and Karen Doerning**

ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207**

Oops!

The contact number for the Lifeline Discount Telephone Service listed in the last issue of *Spinal Courier* should have been **1-800-464-7928**.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Archery Shoot to Benefit the Arkansas Disabled Sportsman's Association

Dear Editor:

A benefit archery shoot will be held at the Mayflower Archery Range **Saturday, June 29, 2002**, to raise money for the Arkansas Disabled Sportsman's Association. There will be a course set up for anyone with a disability who wants to participate or would like to try archery. Also, an archery

demonstration by an archer who has a bilateral upper extremity amputation is scheduled. A cook-out and door prizes will help with the fundraising.

For more information, contact me at **870-935-6875**. See you there!

*Jimmy Ashley
Jonesboro, AR*

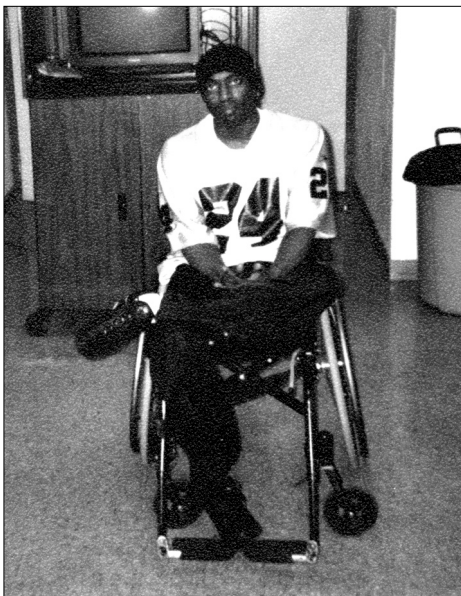
From the Director

Since I first came to the Commission in 1987, I have known Russell Patton, III. Russell has lived with spinal cord injury longer than ASCC has existed — since 1974. He went back to school after his injury and got his CPA. When I met him in 1987 he had just become the Craighead County Treasurer; a position he still holds today. Certainly, when Governor Clinton appointed Russell to complete an unexpired term on the Arkansas Spinal Cord Commission in 1985, he never guessed he would spend the next 16 years at the job — but he did! Russell missed two meetings in all those years, once when he had a State Treasurer's meeting and the other when he and his wife Marie Jose were on their honeymoon!

A fairly quiet guy, Russell was the consummate Board member, supportive, straightforward and always there to help. The only person I know who reads the *Wall Street Journal*, he frequently sent me articles from that and other publications. When budget time came, he always showed up with a calculator (being the accountant that he is) and provided invaluable advice on the "money issues." When clients in his local area needed help, he was an advocate and a friend. And to a very green executive director in 1989, he provided support, shared his experience and was always willing to listen. Russell finished his second term on the Commission in December — our loss and the gain of some other board that he will inevitably volunteer to help.

Many people have made contributions to our Commission, and Russell Patton, III is well at the top of the list!

Cheryl L. Vines



ASCC client Bobby Dandridge recently spoke to a DUI class in Pine Bluff, AR for the new SCI prevention education program, Split Second Decisions. He, along with ASCC Case Manager Bobby Johnson, challenged the members of the class to "Buckle Up, Drive Sober/Drug Free and Think First!"

New Statewide SCI Prevention Education Program

The Arkansas Spinal Cord Commission (ASCC), together with the Arkansas State Highway and Transportation Department, has begun an exciting new spinal cord injury prevention program entitled "Split Second Decisions." According to Patti Rogers, ASCC Client Services Administrator, "The goal of this education program is to reduce the number of deaths and injuries among young adults involved in motor vehicle crashes. The primary focus of Split Second Decisions will be to emphasize the importance of making good decisions to avoid alcohol or drugs while driving and to wear seat belts."

Split Second Decisions targets young adults between the ages

of 21-34. Audiences are selected from schools, employer safety meetings, vocational training facilities and DWI/DUI classes statewide. ASCC Case Managers, along with an individual with a spinal cord injury, an Emergency Medical Technician or State Trooper, make a 45 minute presentation that relates true-to-life experiences and the consequences of making bad decisions.

"We anticipate that 50 presentations during the first year will reach approximately 2,500 participants," stated Patti Rogers. "These participants will be challenged to make positive decisions: **Buckle Up, Drive Sober/Drug Free, Think First!!!**"

Survey for People with Disabilities and Community Participation

Cast your vote!

Do you participate in your community?

Do barriers keep you from participating as much as you'd like?



Please go to the following website: www.rtcfpil.org/survey.htm to complete a survey regarding community participation of people with disabilities and chronic health conditions. We want to hear from you! We'll send you a free copy of our award-winning advocacy tool if you respond promptly.

For more information, or to obtain a paper copy of the survey, call **1-800-255-3555** and ask about the R-One survey.

Ms. Wheelchair Arkansas Pageant

This is the first year for the Ms. Wheelchair Arkansas Pageant. The purpose of the pageant is to focus the public's attention on women's abilities and accomplishments since the onset of disability. Ms. Wheelchair Arkansas will be expected to be a spokesperson representing people with disabilities and will travel to different locations in Arkansas. She will compete in the Ms. Wheelchair America Pageant in 2003.

The pageant and activities will start Friday, **July 26, 2002**, and will conclude Saturday, **July 27, 2002**, in Jonesboro, AR.

To qualify, a contestant must:

- utilize a wheelchair for daily mobility
- be between ages 21 - 60
- have been an Arkansas

resident for at least one full year prior to the date of the pageant

- have had a disability for at least three years

The entry fee for entering the pageant is \$200 — this fee may come from an unlimited number of sponsors such as friends, coworkers, relatives, organizations, business associates, etc. The entry fee will cover food expenses and activities, including a banquet, a self-defense class and a wheelchair dancing instructional class, etc. offered during the weekend of the pageant. The deadline for registration is **May 31, 2002**.

You may contact Ida Esh't, Coordinator of Pageant, for more information and an application at **870-910-6746**, or e-mail her at iesh@mail.astate.edu

Managing Your Bowel Program

Part 1

by Tom Kiser, M.D., ASCC Medical Director

What is a good bowel program? The answer to that question varies when I am working with patients in my clinic. A patient will come to me with a complaint about his/her bowel program usually when there is a radical change or he/she is having a lot of bowel accidents. The Consortium for Spinal Cord Medicine clinical practice guidelines provides a definition of a good bowel program (you can get more information on-line at www.pva.org). A well-designed, effective bowel program minimizes or eliminates unplanned bowel movements; and evacuates stool at regular, predictable times, and in a reasonable time (within 60 minutes of initiation of the bowel program). This type of bowel program avoids colonic over-distention and fecal impaction.

A spinal cord injury (SCI) results in a change in how the gut works. The time it takes for stool to move through

the entire colon takes about twice as long in an individual with a SCI as someone without SCI. The ability to sense stool in the rectal vault and tell the difference between gas and stool is impaired or absent. If your doctor changes your medications, ask him how the medication will affect your bowels. A good bowel program is essential to your health and well-being, and can increase your sense of independence and confidence.

I would like to give you some ideas and methods that may help you

improve on your bowel program. I will try and cover the basics and give you some things that have worked well for my patients.

1. A **scheduled** use of mechanical (digital stimulation) and/or chemical (biscodyl, magic bullet, therevac) **stimulation** helps to effectively evacuate stool from the rectal vault.

2. A consistent **diet with at least 15 grams of fiber** is recommended. Any increase in fiber intake should be done gradually. In general fiber will slow your bowels and increase the time between bowel movements. If you elect to use

fiber supplements (i.e., metamucil or fibercon tablets) increase your fluid intake, or the extra fiber can cause impaction. I usually advise drinking an extra glass of water when

you take fiber supplements.

3. The recommended **fluid intake** is 40 ml/kg body weight + 500 ml/day. (In everyday terms, about 1/2 oz. per pound of body weight, plus 16 ounces; or for 200 lbs. = about 14 eight oz. glasses of fluid). This **must be balanced with your bladder management**.

4. **Treatment** of chronic constipation in SCI should **start with a balanced diet, good fiber and fluid intake**. Daily



activity should be increased and medication that can cause constipation should be reduced or eliminated. Classic constipating medications are any narcotics (morphine, hydrocodone, oxycodone, etc.), tricyclic antidepressants (amitriptyline, nortriptyline, etc.) and anticholinergics (benadryl, atarax, chlortrimeton, etc.), and bladder medication (oxybutynin, tolderiodene, etc).

5. If you are experiencing constipation one of my favorite things to prescribe is a couple of doses of **mineral oil** (2 to 3 tablespoons of oil mixed with juice). This lubricates the gut and will soften it and keep the stool from drying out in the colon and causing bowel impaction. Often after a couple of doses of oil, the addition of a laxative will work more effectively.

6. Last, but not least, **only make one change at a time** in your bowel program. Give it a trial of at least a week before making any other changes. If you change too much too soon, you never know what helped and what did not help.

In part two of this article, I will discuss surgical options of bowel management.

New West Memphis Staff

The ASCC office in West Memphis would like to introduce the latest addition to the administrative support staff in the Regional III South Area, Quanetta Sanford. Quanetta is a long-time resident of Forrest City and a recent graduate of Crowley Ridge Technical Institute in Secretarial Word Processing. She is currently enrolled at East Arkansas Community College pursuing an Associate of Applied Science degree in Administrative Office Technology.

Quanetta is quickly learning about ASCC and is enjoying working with the West Memphis ASCC Case Manager, Sharon McCoy, and the region's clients. In her spare time, Quanetta is a fishing enthusiast and is looking forward to experiencing quality fishing time in the surrounding counties.

Please join us in welcoming Quanetta to the West Memphis ASCC office!



Quanetta Sanford is the new support staff person in West Memphis.

Money Talks: 11 Things to Know about Social Security

by Dan Jones, Vice President, Investments, at Raymond James & Associates

Since childhood, we've heard about Social Security, deposited earnings into it and understood the program will be there for disability and in our retirement future. Yet, most people don't know much more about it than that. Here's a short list of useful facts.

1. Social Security benefits do not automatically start coming in the mail the first day of full retirement age. You **must apply** for them. The easiest way is to set up an appointment with your local Social Security office or call **800-772-1213**.

2. To receive an official statement of your Social Security earnings, an estimate of current disability and death benefits, or projected future retirement benefits, fill out form *SSA7004, Request for Social Security Statement*, available at your local office.

3. If you do not find and correct errors in your Social Security record within three years, they become part of your permanent record. Therefore, check on them every three years or so.

4. You can work during retirement, but earning too much will reduce the benefits you receive. The limits on such earnings are

currently \$10,680. Benefits are reduced by \$1 for every \$2 you earn above this amount. You can work after age 65 as much as you want and receive benefits without limits on your earnings, although they may become taxable.

5. You can increase the size of your retirement benefit by delaying collection and remaining on the job past full retirement age. This high benefit comes from extra earnings toward your account in which a delayed retirement credit is awarded for continued employment, ranging from 3% to 8% of your benefit, depending on your date of birth.

6. For people born after 1937, full retirement age will increase. For example, if you were born in 1940, this is 65 years and six months; born in 1950, it is 66. Anyone born in 1960 or later will be eligible at age 67.

7. Social Security **disability benefits do not continue past full retirement age**. Retirement benefits **must then be applied for** to replace disability benefits.

8. There is a limit on how much you can earn and still receive disability benefits. Beginning January 1, 2002, a beneficiary can earn

\$780 a month and remain eligible for benefits; the amount for 2001 was \$740. The Social Security Administration (SSA) uses the term *substantial gainful activity* (SGA) to determine if work is substantial enough to make a person ineligible for benefits. Under the new rule, monthly SGA earnings limits will be adjusted annually based on increases in the national average wage index. This amount applies to people with disabilities other than blindness.

9. Ex-spouses, widows and divorced widows may be eligible for benefits on a spouse's record. Provided requirements are met, they all may collect on the same worker's record.

10. Two Social Security trust funds are available: one to finance retirement and survivors benefits, and the other for the disability program. Money not used to pay current benefits is invested in U.S. Government Treasury bonds, bills or notes.

11. There is a limit to the amount of benefits that can be paid on each Social Security record. Called the *family maximum*, it is generally around 150-180% of the worker's

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Personal Care Limitations of Arkansans and Persons with a Spinal Cord Injury or Spina Bifida

Most of us don't think twice about taking care of ourselves. Getting out of bed in the morning, using the toilet, brushing our teeth and feeding ourselves are all personal care activities we are used to doing. However, when you have a disability, performing personal care activities can not be taken for granted. For you, taking care of yourself may mean relying on help from others.

Although health care professionals have long recognized that adults with disabilities have personal care limitations and thus need assistance, the percentage of the general adult population requiring help has been difficult to determine. Recently three state government agencies, the UAMS University Affiliated Program, the Arkansas Spinal Cord Commission and the Arkansas Department of Health, collaborated in a joint project to provide more accurate estimates. The project determined the percentage of the general adult population with personal care limitations and, for comparison purposes, the percentage of personal care limitations in two well-known groups with physical disabilities — persons with spinal cord injuries (SCI) or spina bifida (SB).

During 1999, the adult population over age 18 was randomly surveyed about their personal care limitations through the federally sponsored Behavioral Risk Factor Surveillance Survey (BRFSS). In a separate effort, persons over age 18 with spinal cord injury or spina bifida were also asked about their personal care activities. In the BRFSS survey, respondents were classified as "disabled" if they were 1) limited in the amount or kind of work, or 2) had trouble learning, remembering or concentrating, or 3) used special equip-

ment or personal assistance for mobility. Respondents who answered "yes" to any of these questions were asked about their personal care limitations.

Overall, 2997 persons in the general population, 703 persons with SCI and 133 persons with SB were surveyed. Using the above definition of disability, 21.6 percent of the Arkansas general population indicated some type of disability.

The table below indicates the degree of difficulty in performing, unassisted, four personal care activities for each study group. Eighty percent or more of the general population had no difficulty performing any activity and only 1-2 percent or less could not perform any activity. While the degree of difficulty was about the same for both the SCI and SB group for bladder control, they were different in degree of difficulty for walking, bathing, and eating and drinking.

The project's final report is scheduled for release in the summer of 2002; however, some preliminary conclusions have been reached. Although a substantial percentage of the general population has a disability, less than 2 percent are not able to perform their personal care needs. Also, advanced age, say over 65, without the presence of other limitations, is not adequate to define disability.

Although the SCI and SB groups both have spinal cord disabilities, there are significant differences in their ability to perform personal care needs. These differences are a function of age and vertebral level of injury. Generally speaking, among persons with SCI, a greater percentage of persons with paraplegia can take care of their own needs than those with tetraplegia. However, persons with paraplegia lose their ability to take care of themselves with advancing age while persons with tetraplegia basically stay the same.

Difficulty of Performing Personal Care Activities			
	General	SCI	SB
 percents		
<u>Bathing</u>			
No difficulty	87.9	44.5	65.4
Some difficulty	10.9	22.5	20.3
Not able to do it	1.2	33.0	14.3
<u>Eating, Drinking</u>			
No difficulty	97.0	78.0	94.0
Some difficulty	2.9	14.6	4.5
Not able to do it	.1	7.4	1.5
<u>Bladder Control</u>			
No difficulty	82.2	15.1	13.5
Some difficulty	16.9	20.7	26.3
Not able to do it	.9	64.2	60.2
<u>Walking</u>			
No difficulty	81.4	6.4	27.1
Some difficulty	17.5	11.1	13.5
Not able to do it	1.1	82.5	59.4

Sleep Apnea Syndrome in SCI

by Stephen P. Burns, M.D., Assistant Professor of Rehabilitation Medicine, University of Washington School of Medicine

Sleep apnea syndrome is a disorder characterized by frequent, brief pauses in breathing during sleep, resulting in reduced oxygen flow to the brain. The disorder occurs in 4% of the general population, most commonly in middle-aged men, and is a common cause of daytime sleepiness and cognitive dysfunction in the areas of attention, concentration, complex problem solving and short-term recall. Sleep apnea is a serious medical problem because it is associated with increased rates of motor vehicle accidents, hypertension, depression and mortality.

Sleep apnea is significantly more common in persons with SCI, especially those with tetraplegia, among whom an estimated 25% to 40% have the disorder. A number of factors may contribute to this high prevalence. Obesity is relatively common in this population, and individuals with SCI are predominantly males. Both of these are known risk factors for sleep apnea in the general population.

Weakness of respiratory muscles may contribute to the problem, especially in persons with tetraplegia, because the muscles cannot easily interrupt episodes of apnea. The use of sedating antispasticity medications such as baclofen is also considered a potential risk factor because these drugs are known to slow down the breathing apparatus.

Several additional factors may predispose the SCI population to sleep apnea. The supine (lying on one's back) sleeping position is known to markedly increase the rate of obstructive breathing episodes in the non-SCI population. Many individuals with SCI are unable to change position

while in bed, which may result in increased time spent in the supine position.

Persons with tetraplegia often rely on neck and upper chest muscles to help with breathing because the diaphragm muscle may not have normal strength. These muscles become inactive during the rapid eye movement stage of sleep, further compromising the individual's ability to breathe. Nasal congestion is also common in SCI due to disruption of the autonomic (automatic) nervous system, and this further obstructs the airway.

Sleep apnea is often successfully treated in the general population through weight loss, avoidance of the supine sleeping position and use of continuous positive airway pressure (CPAP) therapy, which uses a mask that fits over the nose and is attached to an air pumping device.

Unfortunately, treatment in the SCI population is more difficult. So far, CPAP has not been accepted well by many persons with SCI, possibly because limited upper limb function makes repositioning or adjusting the mask difficult. In previous studies, persons with SCI who were able to tolerate the CPAP showed decreased frequency of apnea episodes and reported increased daytime alertness.

Researchers at the UW (University of Washington) are completing a study of patients with SCI who also have sleep apnea. This study is measuring sleepiness and other symptoms of sleep apnea, and evaluating the types of treatment currently being used by patients.

Continued on page 8 - see "Sleep Apnea Syndrome in SCI"



ASCC Executive Director Cheryl Vines presents a plaque of appreciation to former Commission Member Russell Patton, III of Jonesboro in January. Mr. Patton served 16 years as a member of the Arkansas Spinal Cord Commission, three as chairperson.

Youth Leadership

Continued from page 1

applications, contact Barry Vuletich, Executive Director, Governor's Commission on People with Disabilities at **501-296-1626** or YLF Chair Carol Rogers at **870-773-2807**. Applications are also available from the ASCC Central Office at **800-459-1517**.

Social Security

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benefit. If this limit is exceeded, family members' benefits are reduced proportionately.

Social Security is a significant resource for many people who have disabilities or are retired. Spend some time with your financial planner and learn what part these benefits should play in your future.

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Sleep Apnea Syndrome in SCI

Continued from page 7

This is expected to lead to another study investigating a new treatment and comparing it to conventional treatment.

Sleep apnea may be even more common in the newly injured SCI population since respiratory muscle weakness is more severe in the first several weeks following injury. A study is currently underway at the UW to investigate the prevalence of sleep apnea in newly injured patients (within three to five weeks after injury) and the extent to which the resulting cognitive dysfunction interferes with rehabilitation.

It is possible that adjusting to the CPAP early on in the rehabilitation

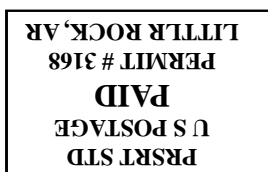
process may improve tolerance of the device over the long run and help people avoid sleep apnea and its associated problems in the future. It also may help patients to participate fully in therapies and learn the information and skills needed to take care of themselves after leaving the hospital.

For more information about sleep apnea, contact:

- American Academy of Sleep Medicine
6301 Bandel Road, Suite 101
Rochester, MN 55901
507-287-6006
Web site:
<http://www.aasmnet.org>

- American Sleep Apnea Association
1424 K Street NW, Suite 302
Washington, DC 20005
202-293-3650
Web site:
<http://www.sleepapnea.org>

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